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ABSTRACT

This paper discusses the attitudes of terminally ill adolescent patients towards their illness and their behaviors during their treatment. Preliminary results are reported on an ongoing study of 12 boys and six girls (age 8-21) with metastatic pediatric solid tumors and lymphomas that failed to respond to conventional treatment. Interviews of patients and parents, daily systematic observations of patients and people with whom they interacted, and daily ratings of the patients by nurses and parents were utilized in a research design with experimental and control groups. Findings indicate that terminally ill adolescents have the same concerns as their healthy peers. Severely ill adolescents have truncated time frames and a high sense of immortality. Their lives are present-oriented and focused on getting through their treatment. Despite knowledge of the gravity of their conditions, terminally ill youth do not view themselves as about to die. Dependence/independence conflicts appear to be exacerbated for these young people. Frequently those under 15 years of age rebel against authority figures. Physical and emotional dependence appear to increase as treatment progresses. Some regressive behavior occurs. It is suggested that treatment models which emphasize achieving ego integrity through acceptance of death appear to be inappropriate for terminally ill adolescents. (Author/RH)

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The Adolescent With a Life-Threatening Illness: Cultural Myths and Social Realities

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MOST STUDIES OF HOSPITALIZED POPULATIONS HAVE BEEN CASE STUDIES AND ANECDOTAL REPORTS. PIONEER__ STUDIES OF CHILDREN WITH CANCER CONDUCTED BY CHODOFF AND HIS GROUP AT NIH ATTEMPTED TO IDENTIFY COPING STRATEGIES BY FAMILIES AND PATIENTS WITH CANCER (CHODOFF, ET AL., 1964). RECENT STUDIES ABOUT PATIENTS WITH LIFE-THREATENING DISEASES HAVE DESCRIBED THE PATIENTS AS BECOMING MORE WITHDRAWN AS THEIR CONDITIONS BECOME WORSE. (SPINETTA, RIGLER, & CARON, 1974). IN ADDITION, THERE HAS BEEN MUCH ATTENTION GIVEN TO DEVELOPING A MODEL TO HELP PATIENTS EFFECTIVELY COPE WITH THEIR ILLNESSES. THE MODEL STRESSES AN ACCEPTANCE OF DEATH. THE RESULTS OF OUR STUDY SUGGEST SOMETHING QUITE DIFFERENT: AN ADOLESCENT WITH A LIFE-THREATENING DISEASE REMAINS ENGAGED WITH THE ENVIRONMENT. FOR THE ADOLESCENT, COPING WITH A LIFE THREATENING DISEASE, IS NOT NECESSARILY LEARNING TO ACCEPT THE PROBABLE AND INEVITABLE OUTCOME OF DEATH.

THE STUDY WAS DONE IN COLLABORATION WITH THE PEDIATRIC ONCOLOGY BRANCH OF THE NATIONAL CANCER INSTITUTE. SUBJECTS WERE 12 BOYS AND 6 GIRLS WHO RANGED IN AGE FROM 8-21. THESE WERE ADOLESCENTS WITH METASTATIC PEDIATRIC SOLID TUMORS AND LYMPHOMAS THAT FAILED TO RESPOND TO CONVENTIONAL TREATMENT. ADOLESCENTS WERE RANDOMLY ASSIGNED BY THE ONCOLOGY STAFF TO RECEIVE CHEMOTHERAPY IN LAMINAR AIR FLOW UNITS (EXPERIMENTAL GROUP) OR ON THE REULAR PEDIATRIC ONCOLOGY WARD (CONTROL GROUP). LAF UNITS ARE SMALL ROOMS, APPROXIMATELY 8' X 10', IN WHICH AN ADOLESCENT RECEIVES TREATMENT UNDER STERILE CONDITIONS (SLIDE 1) BECAUSE OF THE IMMUNO-SUPPRESSIVE EFFECT OF CHEMOTHERAPY, RESISTANCE TO INFECTION IS LOW AND ADOLESCENTS ARE PLACED IN LAF ROOMS TO MINIMIZE THE POSSIBILITY OF INFECTION—A POTENTIALLY FATAL COMPLICATION. TO REDUCE FURTHER POTENTIAL SOURCES OF ENDOGENOUS AND EXOGENOUS INFECTION, THE ADOLESCENTS TAKE ORAL ANTIBIOTICS, USE SPRAYS AND DOUCHES, TAKE BATHS TWICE DAILY, AND ARE MAINTAINED ON A SPECIAL LOW-BACTERIA DIET. MEDICAL PERSONNEL AND VISITORS IN THE FLOW ROOM MUST BE IN STERILE, SURGICAL GARB, INCLUDING FACE MASKS AND PLASTIC GLOVES, THEREBY ELIMINATING SKIN-TO-SKIN CONTACT. (SLIDE 2).

OTHERS MAY VISIT OUTSIDE THE ROOM BUT ARE SEPARATED FROM THE PATIENT BY A PLASTIC CURTAIN. (SLIDES 3 & 4).

(SLIDE 5) THE EXPERIMENTAL DESIGN UTILIZED MULTIPLE METHODS: INTERVIEWS OF PATIENTS AND PARENTS, DAILY SYSTEMATIC OBSERVATIONS OF PATIENTS AND OF THOSE WITH WHOM THEY INTERACTED, AND DAILY RATINGS OF THE PATIENTS BY NURSES AND PARENTS. DATA OBTAINED FROM THESE SOURCES WILL ALLOW US TO ASSESS VARIOUS EMOTIONAL STATES, SOCIAL BEHAVIORS, AND CONCEPTUALIZATIONS OF ILLNESS.

A STRUCTURED INTERVIEW WAS ADMINISTERED ONCE TO EACH PATIENT AND HIS/HER MOTHER BEFORE THE BEGINNING OF CHEMOTHERAPY. AFTER RECOVERY FROM CHEMOTHERAPY (3-8 WEEKS) THE STRUCTURED INTERVIEW WAS REPEATED FOR THE PATIENT. THE INTERVIEWS DEALT WITH QUESTIONS SPECIFIC TO THE ILLNESS AND TREATMENT AS WELL AS TO MORE GENERAL QUESTIONS ABOUT CAUSALITY, HEALING, AND ABOUT THE PATIENT'S INTERACTIONS WITH OTHERS IN HOME AND HOSPITAL SETTINGS.

FIFTEEN-MINUTE OBSERVATIONS WERE CONDUCTED 5 DAYS A WEEK ACCORDING TO A RANDOM SCHEUDLE. INTERACTIONS BETWEEN THE PATIENT AND ONE SIGNIFICANT OTHER WERE CODED ALONG FOUR DIMENSIONS (SLIDE 6). ROLE INDICATED WHETHER THE SUBJECT INITIATED, RECIPROCATED, OR IGNORED AN INTERACTION, OR WAS NOT INTERACTIVE (NON-SOCIAL). "BEHAVIOR" DENOTED ONE OF 7 BEHAVIORS INCLUDING SLEEPING, PLAYING, BEING PHYSICAL, PASSIVE, HAVING A MEDICAL PROCEDURE, PROTESTING OR SPEAKING. THE COMMUNICATION DIMENSION FURTHER DESCRIBED THE BEHAVIORS. EXAMPLES OF THE 10 COMMUNICATIONS ARE: NOT TALKING, PROSOCIAL, SEEKING INFORMATION ABOUT THE ILLNESS, AND DEPENDENCY. THE AFFECT DIMENSION REFLECTS A RANGE OF EMOTIONAL EXPRESSION FROM PLEASANT TO NO AFFECT TO UNPLEASANT. THE FINAL FORM OF THE OBSERVATION SYSTEM REPRESENTS A COMBINATION OF (1) A SYSTEM USED TO OBSERVE PRIMATES, (2) A TAXONOMY OF BEHAVIORS BASED ON PILOT OBSERVATIONS, AND (3) BEHAVIORS OF THEORETICAL INTEREST. FROM OUR OBSERVATION SYSTEM, APPROXIMATELY 700 UNIQUE BEHAVIORS CAN BE SCORED OVER A GIVEN OBSERVATION PERIOD.

OUR STUDY WAS DESIGNED TO ANSWER FOUR BASIC QUESTIONS (SLIDE 7). I HAVE

CHOSEN TO DISCUSS ONLY ONE PART OF THE RESEARCH: THE ADOLESCENT PATIENTS; THEIR ATTITUDES TOWARD THEIR ILLNESS AND THEIR BEHAVIORS DURING THEIR TREATMENTS. BECAUSE DATA ANALYSIS IS STILL TAKING PLACE, I CAN ONLY REPORT THE PRELIMINARY RESULTS.

PERHAPS THE MOST STRIKING FINDING IS ALSO THE ONE THAT SOUNDS MOST MUNDANE, THAT IS, ADOLESCENTS WHO ARE SUFFERING AND IN SOME CASES, DYING FROM CANCER, ARE STILL ADOLESCENTS. THEY ARE CONCERNED WITH THE SAME THINGS WHICH CONCERN HEALTHY ADOLESCENTS: APPEARANCE, MEMBERS OF THE OPPOSITE SEX, CAREER CHOICES, BEING ACCEPTED BY PEERS. FOR EXAMPLE, ONE OF OUR SUBJECTS, WHO HAD AN ARM AMPUTATION AND BILATERAL THORACOTOMIES FOR METASTASIS WAS FORCED TO DELAY HIS CHEMOTHERAPY BECAUSE HE HAD BEEN EXPOSED TO MONONUCLEOSIS WHILE KISSING HIS GIRL FRIEND. ANOTHER ADOLESCENT'S MAJOR WORRY WAS WHERE SHE COULD BUY BLUEJEANS THAT WOULD FIT NOW THAT SHE HAD LOST SO MUCH WEIGHT AFTER CHEMOTHERAPY.

OUR SICK ADOLESCENTS HAVE TRUNCATED TIME FRAMES AND HIGH SENSES OF IMMORTALITY. THIS IS SIMILAR TO WHAT WOULD BE EXPECTED OF HEALTHY ADOLESCENTS. OUR ADOLESCENTS DO NOT HAVE DEFINITE PLANS FOR THE FUTURE, NOR DO THEY DWELL UPON THEIR "HEALTHY" PASTS. THEIR LIVES ARE PRESENT-ORIENTED WITH ONE GOAL—GETTING THROUGH THEIR TREATMENT. DESPITE KNOWLEDGE OF THE GRAVITY OF THEIR CONDITIONS (2% SURVIVOR RATE IN SOME CASES), OUR ADOLESCENTS DO NOT VIEW THEMSELVES AS ABOUT TO DIE. INSTEAD THEY GEAR THEMSELVES UP TO "LICK CANCER" —IT BECOMES A CHALLENGE. AS ONE OF OUR SUBJECTS STATED, "SOMEONE'S GOT TO MAKE UP THE 2%."

PERHAPS ONE OF THE MOST CRITICAL ASPECTS OF SUCH A SERIOUS ILLNESS IS THAT THE DEPENDENCE/INDEPENDENCE CONFLICT EXPERIENCED BY ALL ADOLESCENTS IS EXACERBATED FOR THE ILL ADOLESCENT. ADOLESCENCE IS A PERIOD OF BECOMING

INDEPENDENT AND YET OUR ADOLESCENTS ARE THROWN INTO A SITUATION REQUIRING ALMOST TOTAL DEPENDENCE ON NURSES, PARENTS, DOCTORS, AND DRUGS. CONTROL MUST BE RELINQUISHED ALMOST TOTALLY BY THESE ADOLESCENTS. THEY ARE AT THE MERCY OF DOCTORS' AND NURSES' SCHEDULES; THEY ARE TOLD WHAT AND HOW TO DO THINGS; AND IN MANY CASES, THEIR BODIES ARE NOT IN CONTROL AS THEY VOMIT FREQUENTLY FROM THEIR MEDICATION, EXPERIENCE DIARRHEA, OR ARE GIVEN DIURETICS. NEVERTHELESS, OUR PATIENTS RESPOND AS NORMAL ADOLESCENTS. THAT IS, THEY FIGHT, IF NOT TO RETAIN THE CONTROL THEY DO HAVE, THEN AT LEAST TO REBEL AGAINST THE AUTHORITY FIGURE WITH THE CONTROL. WE HAVE FOUND THIS TO BE ESPECIALLY TRUE OF THE YOUNG ADOLESCENTS (UNDER 15 YEARS OLD). IT IS THIS "TYPICAL ADOLESCENT" BEHAVIOR WHICH MAKES THEM DIFFICULT PATIENTS FOR THE MEDICAL STAFF AND TRYING SUBJECTS FOR THE RESEARCH TEAM. THESE ARE THE SUBJECTS WHO REFUSE TO EAT, REFUSE TO TAKE THEIR PROPHYLACTIC MEDICATIONS, AND REFUSE TO ALLOW FURTHER OBSERVATIONS. ONE ADOLESCENT GIRL DESCRIBED LAF BY STATING, "IT'S PRETTY BAD. EVERYTHING IS REGULATED. YOU HAVE TO GET BLOOD DRAWN; HAVE TO HAVE BATHS TAKEN, YOU HAVE TO HAVE A CERTAIN AMOUNT OF EXERCISES DONE—IT'S REALLY A DRAG." SHE WAS ALSO ONE OF THREE PATIENTS WHO DROPPED OUT OF OUR STUDY. HER REFUSAL REFLECTED ADOLESCENT INDEPENDENCE—SHE WAS TIRED OF HAVING THINGS DONE TO HER AND REFUSING TO PARTICIPATE FURTHER IN OUR STUDY WAS AT LEAST ONE AREA OF HER LIFE OVER WHICH SHE HAD CONTROL.

ALTHOUGH THE CONTROL ISSUE IS ONE AGAINST WHICH THE ADOLESCENT CAN FIGHT, PHYSICAL AND EMOTIONAL DEPENDENCE APPEAR TO INCREASE AS TREATMENT PROGRESSES. MOST OF OUR ADOLESCENTS DISPLAY A CERTAIN AMOUNT OF REGRESSIVE BEHAVIOR: BEING FED BY A PARENT, BECOMING AGITATED AND CLINGY WHEN A PARENT LEAVES A BEDSIDE, WHINING DURING ROUTINE PROCEDURES, AND BECOMING OVERLY DEMANDING ARE A FEW EXAMPLES. THIS BEHAVIOR IS TRANSIENT AND USUALLY

IS NOT PRESENT BY THE TIME THE PATIENT LEAVES THE FLOWROOM. DURING THE SECOND, POST-FLOW INTERVIEW WITH ONE 16-YEAR OLD GIRL, THE GIRL DESCRIBED HERSELF AS NOT MINDING THE PROCEDURES AND TOLERATING THE WHOLE EXPERIENCE WELL. "IT'S NOT SO BAD, REALLY," SHE TOLD ME. THIS IS THE SAME PERSON WHO WAS OBSERVED BY BOTH THE MEDICAL AND RESEARCH STAFF AS THROWING TANTRUMS DURING MEDICAL PROCEDURES AND PROTESTING AND COMPLAINING A GREAT DEAL.

THUS FAR I HAVE ATTEMPTED TO PRESENT A GENERAL PICTURE OF THE ADOLESCENT WHO FACES DEATH FROM CANCER. I HAVE TRIED TO PLACE THE ADOLESCENT PATIENT'S VIEWS AND BEHAVIORS IN THE CONTEXT OF NORMAL ADOLESCENT DEVELOPMENT. IN THE REMAINING TIME I WOULD LIKE TO LOOK BRIEFLY AT DATA FROM ONE PATIENT IN ORDER TO GIVE BOTH A MORE IN-DEPTH PICTURE OF THE ADOLESCENT PATIENT AS WELL AS A CLEARER PICTURE OF OUR RESEARCH EFFORT.

I HAVE CHOSEN A 19-YEAR-OLD ADOLESCENT WITH OSTEOGENIC SARCOMA. (SLIDE 8). THESE GRAPHS REPRESENT SOME OF THE RESEARCH INDICIES WE STUDY. THE FIRST GRAPH CHARTS THE DEGREE TO WHICH HE SUFFERS FROM STOMATITIS (MOUTH SORES). THE SECOND CHARTS TEMPERATURE, THE THIRD, TOTAL VOCAL OUTPUT AND THE FOURTH GRAPH CHARTS PASSIVE BEHAVIOR. IT IS INTERESTING TO NOTE THAT VOCAL BEHAVIOR (AN INTERACTIVE BEHAVIOR) REMAINS FAIRLY HIGH AND CONSTANT DURING PERIODS OF GREATEST PHYSICAL DISCOMFORT (HIGHER TEMPERATURE AND GREATER STOMATITIS). HOWEVER, VOCAL BEHAVIOR DROPS OFF AS THIS ADOLESCENT'S PHYSICAL CONDITION AMELIORATES. OTHER DATA FROM THIS ADOLESCENT SHOW THAT AS PHYSICAL DISTRESS RESOLVES, SLEEP GOES TO ITS HIGHEST POINT. THUS, AT A TIME WHEN THE PATIENT IS MOST ILL, HE INTERACTS MORE THAN WHEN HE IS PHYSICALLY BETTER. THIS IS FURTHER SUPPORTED BY NOTING THAT TOTAL OUTPUT (THAT IS, THE TOTAL NUMBER OF BEHAVIORS EMITTED DURING AN OBSERVATION PERIOD) IS GREATEST DURING WEEK TWO (A TIME OF RELATIVE PHYSICAL DISTRESS), AND GRADUALLY DIMINISHES THROUGH THE REST OF THE TREATMENT COURSE.

IN ADDITION TO THESE KINDS OF ANALYSES OF THE OBSERVATIONAL DATA, WE WILL BE ANALYZING NURSE AND PARENT RATING FORMS OF THE ADOLESCENT'S DAILY MOODS AND BEHAVIORS. WE WILL COMPARE THE RATINGS WITH PHYSIOLOGICAL DATA, WITH OUR OBSERVATIONAL DATA, AND WITH EACH OTHER. WE ALSO WILL BE CODING AND ANALYZING PARENT AND ADOLESCENT INTERVIEWS ALONG SEVERAL PREDETERMINED DIMENSIONS.

STUDYING PATIENTS WITH LIFE-THREATENING ILLNESSES IS STILL A FAIRLY NEW AREA OF INQUIRY. FINDINGS PRESENTED IN THE LITERATURE USUALLY REFER TO ADULT POPULATIONS. WE ARE TOLD THAT DYING PATIENTS AND THOSE AROUND THEM GO THROUGH A PERIOD OF MUTUAL DISENGAGEMENT AS THEY "FACE AND ACCEPT" DEATH. AS THE TITLE OF THIS PAPER SUGGESTS, WE HAVE FOUND THAT THERE IS A DISCREPANCY BETWEEN THE CULTURAL MYTH AND THE SOCIAL REALITY OF THE ADOLESCENT WITH LIFE-THREATENING DISEASE. ALTHOUGH THERE ARE VICISSITUDES IN MOODS AS A FUNCTION OF THE ILLNESS, THE ADOLESCENT DOES NOT DISENGAGE, NOR DO THE STAFF AND PARENTS. PERHAPS THE ADOLESCENT'S STAGE OF LIFE IS ON HIS/HER SIDE IN COPING WITH THE THREAT OF DEATH. THE TYPICAL ADOLESCENT FEELINGS OF IMMORTALITY AND A LACK OF PLANNING FOR THE FUTURE MAY FACILITATE THE DENIAL OF THE ILLNESS AND THEREBY KEEP THE ADOLESCENT VERY MUCH ENGAGED IN THE PROCESS OF LIVING.

MOST OF THESE ADOLESCENTS ACCEPT READILY THE FACT OF ILLNESS WITHOUT BECOMING MORBIDLY OBSESSED WITH THE REALITY OF THE PROBABLE OUTCOME. THIS IS NOT A DENIAL OF THE IMPACT OF THE DISEASE BECAUSE THESE ARE PEOPLE WHO ARE CONSTANTLY REMINDED OF THE POTENTIAL FATALITY OF THEIR ILLNESSES: THEY OFTEN MUST WATCH AS OTHER PATIENTS WHO HAVE BECOME FRIENDS, DIE. BUT AS ONE OF OUR ADOLESCENTS WHO HAS A 4.0 AVERAGE AT COLLEGE AND IS HOLDING DOWN A PARTIME JOB SAID, "WHAT AM I GOING TO DO, SIT AROUND AND THINK, OH BOY,

I'VE GOT CANCER."

HOPE IS HIGH FOR THESE PATIENTS AND THEIR FAMILIES, AND THIS MAY BE SOMEWHAT DISCONCERTING FOR US PROFESSIONALS WHO KNOW WHAT THE ODDS REALLY ARE. HOWEVER USEFUL THE ACCEPTANCE OF THE REALITY OF DEATH MAY BE IN HELPING AN ADULT ACHIEVE WHAT ERIKSON CALLS "EGO INTEGRITY," SUCH CONSOLIDATING, REVIEWING, AND MAKING SENSE OF A PERSONAL HISTORY IS SOMEWHAT IRRELEVANT TO THE PERSON WHO HAS YET TO CREATE A PAST. THUS, ADOLESCENTS WITH CANCER, LIKE THEIR HEALTHY COHORTS, CONTINUE LIVING IN HOPES OF CREATING A FUTURE. WHILE SUCH BEHAVIOR MAY BE DIFFICULT TO UNDERSTAND FROM AN ADULT'S PERSPECTIVE, WE MUST ASK OURSELVES IF THERE REALLY IS ANYTHING "PATHOLOGICAL" IN ACTING "AS IF" THE ADOLESCENT WERE GOING TO GO RIGHT ON LIVING.

AN ADOLESCENT WITH CANCER, EVEN WITH A POOR PROGNOSIS, IS NOT ABOUT TO RELINQUISH LIFE TO THE ODDS. PREPARING ONESELF FOR DEATH IN AN ACTIVE WAY IS MEANINGLESS. OUR ADOLESCENTS DEMONSTRATE THAT THE GENERALIZED NOTION OF THE WITHDRAWING DEPRESSED PATIENT MAY BE A MYTH AND THAT WHAT WE NEED TO CONSIDER IS A MODEL TO HELP PEOPLE LIVE WITH THE THREAT OF DEATH. EVEN IN THE DARKEST HOURS, NEITHER HOPE NOR A SENSE OF REALITY IS LOST. UPON RELAPSING AFTER A 14-MONTH REMISSION AND SWITCHING TO THE LAST DRUG WHICH MIGHT HELP, ONE 12-YEAR OLD PATIENT EXPLAINED, "WELL, I GUESS WE'LL KNOW IN 10 MONTHS IF IT WORKED." THE IMPLICATION WAS, IF HE'S STILL ALIVE.

OUR STUDY REPRESENTS AN ATTEMPT TO LEARN ABOUT THE ADOLESCENTS' UNDERSTANDING OF ILLNESS AND OF THE HEALING PROCESS. HOW DO THEY COPE WITH AN ILLNESS; HOW DO THEY BEHAVE WHILE UNDERGOING TREATMENT; HOW DO THEY RECONCILE THE CATASTROPHE FOR THEMSELVES; AND HOW DOES THE ILLNESS AFFECT FAMILY INTERACTIONS; ARE BUT A FEW OF THE QUESTIONS YET TO BE ANSWERED. ANSWERS TO THESE QUESTIONS ARE IMPORTANT IN UNDERSTANDING CHILD DEVELOPMENT IN GENERAL, AS WELL AS IN HELPING PRACTITIONERS DEVELOP A HOLISTIC APPROACH

TO TREATING SICK CHILDREN. BY UNDERSTANDING THE PATIENTS' AND FAMILIES' PERSPECTIVE OF AN ILLNESS AND BY IDENTIFYING PREDICTABLE PATTERNS OF BEHAVIOR IN ILL CHILDREN WE CAN PLAN MORE EFFECTIVE INTERVENTIONS FOR THE PATIENTS AND FAMILIES. BY DETERMINING WHAT CHILDREN UNDERSTAND ABOUT THEIR ILLNESSES WE CAN PLAN WHEN AND HOW MUCH TO EXPLAIN TO THEM ACCORDING TO THEIR ABILITIES TO ASSIMILATE INFORMATION AT DIFFERENT STAGES OF ILLNESS. WE CAN LEARN WHAT POINTS MAY BE VERY STRESSFUL AND THEREFORE PROVIDE EXTRA PSYCHOLOGICAL SUPPORT; WE CAN DOCUMENT THE NEED FOR PRIVACY AND WITHDRAWAL AND ACT ACCORDINGLY. IF BEHAVIOR AND MOOD CHANGES CAN BE PREDICTED, WE, AS CAREGIVERS, ARE NOT CAUGHT OFF GUARD BY SUDDEN MOOD SHIFTS AND THEREFORE WE CAN COPE A BIT BETTER WITH WHAT MIGHT BE EXAGGERATIONS OF BEHAVIOR AND AFFECT. SUCH KNOWLEDGE CAN ONLY BE GAINED THROUGH WELL-PLANNED SYSTEMATIC RESEARCH.

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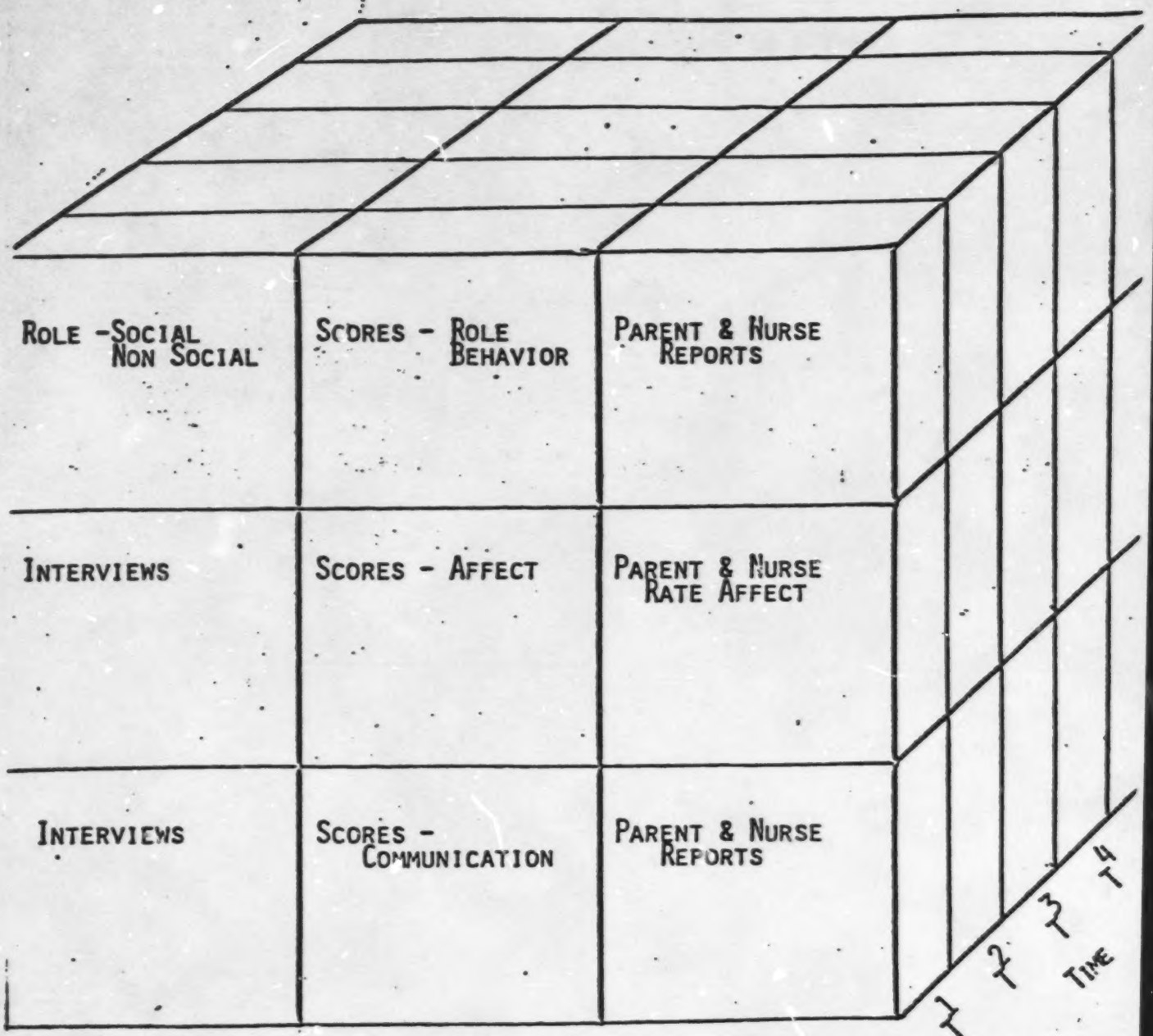
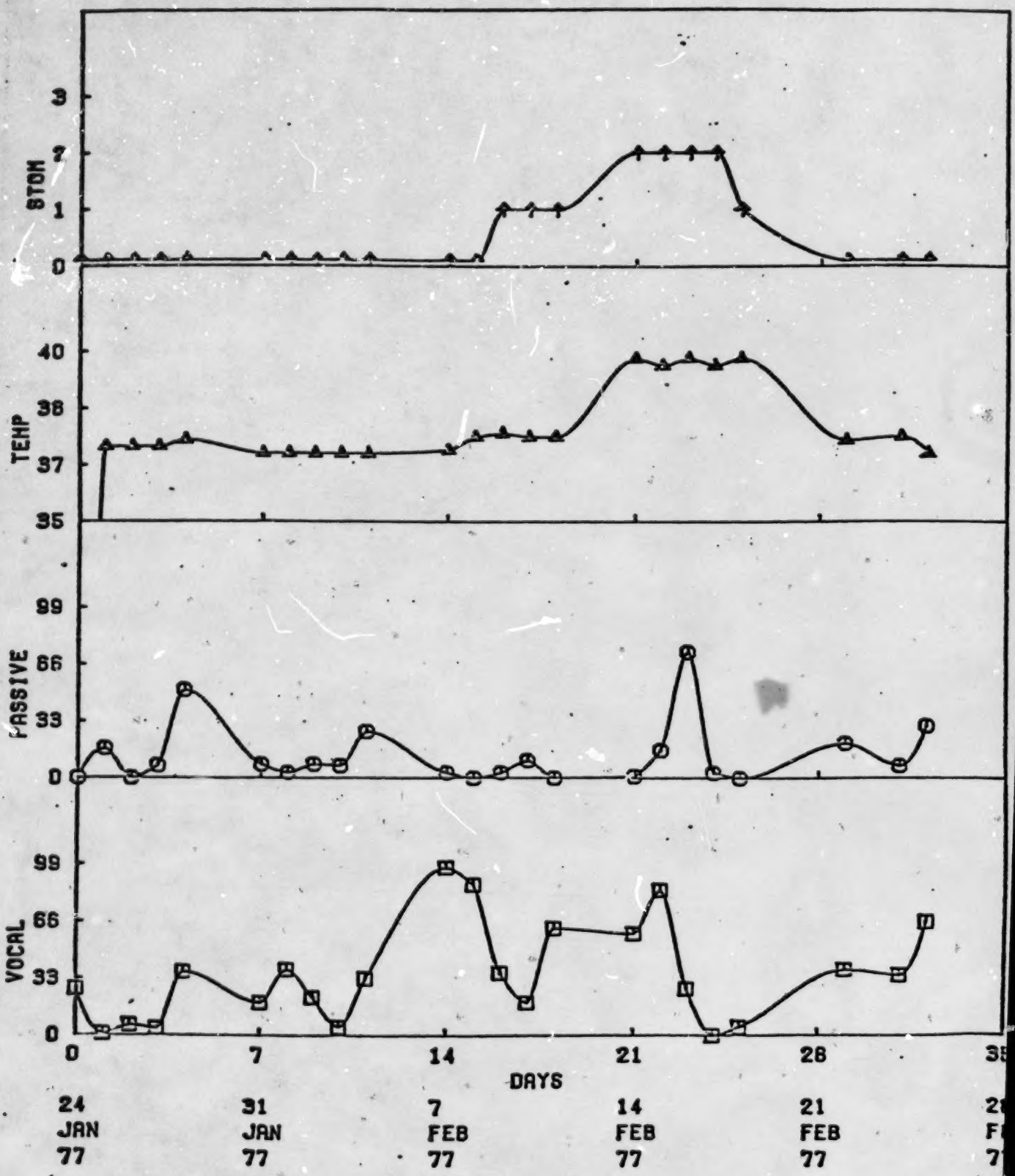

ROLE -SOCIAL
NON SOCIAL
SCORES - ROLE BEHAVIOR
PARENT & NURSE REPORTS
INTERVIEWS
SCORES - AFFECT
PARENT & NURSE RATE AFFECT
INTERVIEWS
SCORES - COMMUNICATION
PARENT & NURSE REPORTS
T1
T2
T3
T4
TIME
CHILD
OBSERVER
PRIMARY INFORMANTS
DATA SOURCE

SLIDE 5

CHILD-OTHER OBSERVATIONAL CATEGORIES

ROLE	BEHAVIOR	COMMUNICATION	AFFECT
NON-SOCIAL	PLAY	NO TALK	NONE
INITIATE	SLEEP	GENERAL CONVERSATION	PLEASANT
RECIPROCATE	VOCAL	DEPENDENCY	HAPPY
RECIP-IGNORE	PASSIVE	TECHNICAL INFORMATION	ANGER
	PHYSICAL	PROSOCIAL	CRYING
	PROTEST	COMPLAIN	RESPONSE TO PAIN
	MEDICAL PROCEDURE	HUMOR	
		PRAISE	
		NON-VERBAL	
		ILLNESS-INFORMATION	

SLIDE 6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SLIDE 8